

# Aging With Developmental Disabilities An Overview

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Because of advances in healthcare, individuals with developmental disabilities have a longer life expectancy than ever before. Increasing attention is being placed on this growing population of individuals throughout all aspects of the healthcare system including, medicine, rehabilitation, and social services. This article will review the demographic trends seen in this population, the effects of aging on individuals with disabilities, and contemporary practices that hold promise to diminish the negative consequences of aging and promote the individual's continued participation in the community. **Key words:** cerebral palsy, developmental disabilities, Down syndrome, intellectual disability

**A**WARENESS of the increasing numbers of individuals with developmental disabilities, who are aging, has led service providers to focus on the needs of these individuals and the system's ability to serve them appropriately. It is estimated that there are between 3.2 and 4.5 million individuals with sensory, mental, physical, or other developmental disabilities that impair their ability to effectively care for themselves.<sup>1</sup> Of these, 641,000 are older than 60 and this number is projected to double by 2030.<sup>2</sup> To prevent unnecessary impairment, maintain functional skill level, and promote independence in this population, there is an increasing awareness of the importance in providing community-based services and supports that focus on older adults with developmental disabilities. Over the last decade, several national and international initiatives have been established focusing attention on the unique needs of this population and promoting a prevention and wellness perspective to healthcare provision for them.

The *US Healthy People 2010*<sup>3</sup> initiative targets the top American healthcare concerns (Box 1). The 2 main goals of the US Healthy People 2010 initiative are to increase the quality and numbers of years of healthy life and eliminate health disparities.

People with disabilities are represented in the objectives used to track progress for these goals. For example, the initiative *Disability and Secondary Conditions* promotes the health of people with disabilities, prevents secondary conditions, and eliminates disparities between people with and without disabilities.<sup>3</sup> Although elders with disabilities are included in the initiative and there is indication that progress is being made in addressing these areas, elders with disabilities are still less likely to have health insurance, to engage in physical activity, and are more likely to be obese, and smoke cigarettes, all factors related to adult onset disease and impairment. Two other national initiatives, *Closing the Gap: A National Blueprint to Improve the Health of Persons With Mental Retardation*<sup>4</sup> and the *Surgeon General's Call to Action to Improve the Health and Wellness of Persons With Disabilities*,<sup>5</sup> focus on promoting a healthy lifestyle and healthy aging and preventing further impairment, disability, and disease. *Closing the Gap* is a national campaign designed to help improve the health of people with intellectual disability. The goals

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**Box 1.**

US Healthy People 2010: Top American healthcare concerns

- Physical activity
- Obesity
- Tobacco use
- Substance abuse
- Responsible sexual behavior
- Mental health
- Injury and violence
- Environmental quality
- Immunization
- Access to healthcare

of the Surgeon General's initiative, *Call to Action on Disability*, are as follows:

- Increase understanding so that people with disabilities can lead long, healthy, and productive lives.
- Increase knowledge among healthcare professionals and provide them with tools to screen, diagnose, and treat people with a disability with dignity.
- Increase awareness, among people with disabilities, about the steps they can take to develop and maintain a healthy lifestyle.
- Increase accessible healthcare and support services to promote independence in people with disabilities.

Globally, the World Health Organization (WHO) also recognizes the growing population of ageing adults with developmental disabilities and their needs. *Healthy Aging-Adults With Intellectual Disabilities*<sup>6</sup> outlines the key issues facing aging adults with developmental disabilities globally and offers specific recommendations to support healthy aging including an emphasis on rehabilitation. Five other WHO documents analyze the health needs of adults with developmental disabilities.<sup>7-10</sup>

Consistent with these initiatives that focus on prevention and wellness, there has been a paradigm shift in how disability is viewed. The reconceptualization of disability from a medical model to a social model significantly impacts the service system, the sup-

ports needed by an individual and the expectations society has for an individual with a disability as he or she ages. The medical model, an impairment-based model that regards disability as a biological abnormality requiring treatment, is being replaced with a social model. The social model conceptualizes disability as a condition that occurs primarily within the context of psychological, social, and environmental constraints, which may interfere with functioning.<sup>11</sup> In addition, rather than defining health as the absence of disability or disease, it is now defined as a global state of social, emotional, and mental well-being.<sup>12</sup> This change in perception supports the need to plan comprehensive programs that support individuals with disabilities, the delivery of supports in the community, and consider the needs, wants, and preferences of the individual.

The need for community-based services and supports for individuals with developmental disabilities has been increasing since the intolerable conditions of large state-run institutions were exposed in the 1960s and 70s. Four major events occurred during the 1970s, enabling the growth of community-based services and supports:

- Passage of the Intermediate Care Facilities/Mental Retardation Program of Title XIX (Medicaid) of the Social Security Act<sup>13</sup>;
- Landmark ruling on the right to treatment in the *Wyatt v Stickney* case<sup>14</sup>;
- Passage of Section 504 of the Rehabilitation Act<sup>15</sup>; and
- Passage of the Education for All Handicapped Children's Act (now called IDEA).<sup>16</sup>

Building on these initiatives, 3 major legislative efforts were passed in the 1980s that mandated that older persons with developmental disabilities be afforded services to meet their unique needs (Table 1).

This trend is continuing as the deinstitutionalization movement grows. In June 1999, the Supreme Court<sup>20</sup> ruled that the states are required to provide community-based services for those with intellectual disabilities if

**Table 1.** Legislation impacting elders with developmental disabilities (1980–1989)

Law	Description
Omnibus Budget Reconciliation Act (1981) <sup>17</sup>	<ul style="list-style-type: none"> <li>• Before admission to a nursing home, a screening must be performed for every person with a developmental disability</li> <li>• Annual review of every person with a developmental disability who resides in a nursing facility</li> <li>• Persons with developmental disabilities who are found to be inappropriately placed in a nursing home must be discharged</li> </ul>
Older American Act Amendments (1987) <sup>18</sup>	<ul style="list-style-type: none"> <li>• Mandated that older persons with developmental disabilities be served under the Act's provisions</li> <li>• Mandated that the Administration on Aging (AOA) collaborate with the developmental disability service system to design and implement appropriate services</li> <li>• OAA programs were opened to elders with developmental disabilities</li> </ul>
Developmental Disabilities Assistance and Bill of Rights Act (1987) <sup>19</sup>	<ul style="list-style-type: none"> <li>• Extended the provisions of the Developmental Disabilities Services and Facilities Construction Act of 1970</li> <li>• Identified service delivery models to accommodate growth in the population and need for trained professionals</li> <li>• Promoted community-based residential services</li> </ul>

appropriate and if the individuals with disabilities agree to treatment in the community. In addition, the Americans with Disabilities Act of 1990<sup>21</sup> ensures access to and participation in senior citizen centers, day-care sites, and social-service centers for individuals with developmental disabilities. Thus, legislation is in place that ensures that individuals with developmental disabilities are becoming members of the community at increasing rates.

The aims of the legislation are greater than simply ensuring community-based living. A major goal of community-based residential programs for adults with developmental disabilities is to promote functional and independent skills in all domains. This requires that services and supports that promote function and independence, as the individual with a developmental disability ages, are in place to ensure success. These supports include health (medical, behavioral, and therapeutic) services, employment, transportation, social activities, spiritual guidance, and assistive technology as needed. Programming must be individualized and a range of supports must be available. Given the legislative, programmatic,

and philosophical changes seen over the last 40 years, it is imperative that service providers recognize the needs of older adults with developmental disabilities and create programs, services, and supports that meet these needs.

## DEMOGRAPHICS

A developmental disability is a chronic, severe disability that is attributable to a mental or physical impairment or a combination of mental and physical impairments, is manifested before the age of 22, results in functional limitations, and indicates the need for services, supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.<sup>1</sup> According to Cooper et al<sup>22</sup> individuals with developmental disabilities represent about 1% of the population. Of these, 12% are older than 65 years. As the number of individuals with developmental disabilities has grown, so has life expectancy. Life expectancy has increased by approximately 250% since the 1930s from 19 years

of age to 70.<sup>23</sup> Unless the individual has a significant disability such as Down syndrome, cerebral palsy (CP), multiple disabilities, or a severe level of cognitive impairment, the life expectancy and age-related medical conditions of elders with developmental disabilities are similar to that of the general population. For instance, over half of those with Down syndrome are expected to survive into their 50s and 13.5% will be alive when they are aged 65.<sup>24</sup> In addition, Janicki and Dalton<sup>25</sup> found that 22% of adults with Down syndrome older than 40 years had Alzheimer's disease, and this rate rose to 56% in individuals older than 60 years.

Women with developmental disabilities present with unique considerations, placing them at greater risk for developing health-related problems than women without developmental disabilities. They receive significantly less preventive care than other women and lead very sedentary lives, which often results in greater risk for cardiovascular diseases (CVDs). For example, participation in breast cancer screening is much less likely if the woman is older and has a disability or functional limitations.<sup>26</sup> Women with CP, in particular, underuse mammography, often leading to delayed diagnosis of breast cancer and less favorable outcomes.<sup>26</sup> Barriers to obtaining this service include lack of information about the benefits<sup>27</sup> transportation challenges, inability to be positioned appropriately<sup>28</sup> in the mammography machine, communication challenges,<sup>29</sup> and negative attitudes from staff.<sup>30</sup> Appropriate services and knowledgeable service providers must be available to provide intervention that meets both the unique challenges presented by the population as well as the age-related healthcare challenges.

## SERVICE SYSTEM

The contemporary service system for older adults with developmental disabilities has evolved from the "normalization" movement of the 1960s. The development of the service

system is grounded in the belief that individuals with developmental disabilities will develop and function optimally if they are integrated into society and afforded the same experiences with the appropriate supports as those without disabilities. The community-based model of care operationalized the "normalization" philosophy. Community-based residential and treatment programs were developing throughout the country by the mid-1970s and by 1991, New Hampshire and the District of Columbia had closed their state-run institutions, and all the individuals with developmental disabilities were placed in community-based residential facilities. Since then, 8 more states have closed all their public institutions.<sup>31</sup> Federal legislation passed over the last 3 decades supports the community-based model of care and provides systems to increase the likelihood that adults and older persons with a developmental disability will become integral members of the community.

Unlike the service system for older Americans without developmental disabilities, which is an age-based service system, the system for those with developmental disabilities is a needs-based system. Age-based services are designed to focus on the needs of the group of older citizens. Services such as Medicare that begins at age 65, irrespective of an individual's strengths or needs, is considered an age-based system. A needs-based service system provides individualized, specialized services,<sup>32</sup> based on the unique strengths, needs, and preferences of the older individual, and is the preferred service system for elders with developmental disabilities. The current focus of service provision is to bridge these 2 service delivery systems (age-based and needs-based) encouraging collaboration and joint planning to ensure that an individual's needs are best met in the most efficient community-based manner as possible. Thus, services to an individual may be drawn from the standard age-based system or from specialized services through a needs-based system of service and support. A needs-based system for older adults with

developmental disabilities includes a complex array of professionals, nonprofessional services, supports, and treatment programs primarily funded through federal and state funding programs such as Medicaid and Medicare.

### **AGE-RELATED HEALTHCARE ISSUES SPECIFIC TO ADULTS WITH DEVELOPMENTAL DISABILITIES**

Individuals with developmental disabilities are at an increased risk for a variety of health-related problems. Although the life expectancy for all the individuals with developmental disabilities has increased, their average life expectancy continues to be less than that of the general population.<sup>33</sup> Specific health issues are associated with elders with developmental disabilities; however, as seen in the general population, obesity and CVD can affect all persons with developmental disabilities.

#### **Obesity and CVD**

Individuals with an intellectual disability have the same, if not a higher, incidence of obesity than adults without an intellectual disability. Yamaki estimated that the obesity rate for adults with intellectual disabilities was significantly higher than that of the general population at each of the four 4-year observation periods of the National Health Interview Survey. For instance, in the time period between 1997 and 2000, 36.4% of adults with intellectual disabilities were considered obese as compared with 20.6% of adults without intellectual disabilities.<sup>34</sup> More recently, Rimmer and Wang<sup>35</sup> measured the height and the weight of 306 adults, a subset of which was intellectually disabled, within the Chicago area. The rate of obesity in people with intellectual disabilities was twice as high in comparison with that of the general population. About 70% of adults with Down syndrome and 60.6% of adults with intellectual disabilities were found to be obese. What is especially alarming is that extreme obesity was 4 times greater in

adult individuals with Down syndrome (19%) and 2.5 times greater for adults with other forms of intellectual disabilities (12.1%) than the general population. In addition to various health conditions such as hypertension, diabetes, heart disease, stroke, and stress, obesity also results in significant societal and personal limitations such as employment and leisure activities.<sup>36</sup> As seen in the general population, obesity in older adults with intellectual disabilities results in higher medical costs for obesity-related chronic health conditions.<sup>37,38</sup> Furthermore, it requires a greater effort on the part of caregivers to assist obese individuals with intellectual disabilities, thus placing caregivers at greater risk for health problems such as low back pain.<sup>36</sup> Lack of physical activity, poor diets, and environmental factors have been linked to obesity in persons with intellectual disabilities.

CVD has also been found to affect those with developmental disabilities. As in the general population, CVD is the leading cause of death in those with an intellectual disability, except for those with Down syndrome.<sup>39</sup> Factors that indicate a higher CVD incidence in this population include longer life expectancy, physical inactivity, and higher dietary fat intake.<sup>39</sup>

Three of the most common types of developmental disabilities are intellectual disabilities, CP, and Down syndrome. As the life expectancy for individuals with these disabilities continues to increase, so does the risk for specific age-related health concerns. In addition to obesity and CVD, individuals with these conditions are at risk for specific healthcare concerns.

#### **Down syndrome**

The onset of age-related changes in sensory, cognitive, and adaptive skills for people with Down syndrome occurs earlier than in other adults with developmental disabilities and earlier than the general population.<sup>40</sup> There is a higher prevalence of Alzheimer's disease in adults with Down syndrome, and it is likely to occur at an earlier

age compared to the general population.<sup>41</sup> For adults with Down syndrome, symptoms of dementia are often associated with other conditions that are treatable such as hypothyroidism/hyperthyroidism, depression, and sensory impairments.

It is estimated that 40% to 45% of adults with Down syndrome between 50 and 70 years of age will develop Alzheimer's disease: an incidence that is 3 to 5 times larger than in the general population.<sup>42</sup> Early symptoms of Alzheimer's disease in older individuals with Down syndrome are similar to those in the general population: loss of logical thinking and memory, diminished abilities to perform activities of daily living, changes in gait and body coordination, and finally loss of bowel and bladder control. Persons with Down syndrome may also develop seizure activity, which is uncommon in the general population. It is recommended that those with Down syndrome be assessed annually starting at age 30 to monitor the loss of skills.<sup>42</sup> Because adults with Down syndrome are known to have cognitive impairments, a decline in activities of daily living may be a better indicator of Alzheimer's disease than memory and cognitive task loss.<sup>43</sup> Assessment tools such as the Vineland Adaptive Behavior Scale II<sup>44</sup> may be helpful to assess the functional decline of those with Down syndrome suspected of having Alzheimer's disease.

There is an indication that those with Down syndrome are often misdiagnosed as having Alzheimer's disease, when in fact they are experiencing clinical depression.<sup>45</sup> The incidence of depression in individuals with Down syndrome is 6% to 12%.<sup>45</sup> Distinguishing the 2 is extremely important for caregiving purposes. In addition to a loss in adaptive skills, affective behavioral changes such as sadness, somatic complaints, crying, and increases in self-injurious or aggressive behaviors can also be seen.<sup>46</sup> A framework that distinguishes among depression without dementia, depression with dementia, and dementia without depression is needed to guide rehabilitative interventions.<sup>45</sup>

## Box 2.

Secondary conditions of concern to older adults with cerebral palsy

- Musculoskeletal deformities
- Pain
- Cervical spine stenosis
- Deconditioning
- Change in skills
- Falls
- Osteoporosis
- Fractures
- Pressure sores
- Emotional issues

## Cerebral palsy

Older adults with CP are at high risk for secondary conditions that cause a loss of function and deterioration of their quality of life.<sup>47</sup> Complications related to musculoskeletal changes include increasing scoliosis, contractures, hip subluxation or dislocation, pathological fractures, and pain contributing to a loss of independent living skills as individuals with CP age (Box 2).

Lower extremity contractures are prevalent in individuals with CP who do not walk (up to 91%), and can be problematic for transfers, positioning, hygiene, and skin protection.<sup>48</sup> In addition, scoliosis appears to show a significant progression over time, which can lead to difficulty sitting and positioning, and has further effects on mobility, comfort, pelvic positioning, independence, skin integrity, and respiration.<sup>49</sup>

Pain, related to musculoskeletal dysfunction, overuse syndromes, and degenerative arthritis, is often reported in adults with CP.<sup>48</sup> Sixty-seven percent of women within one community complained of pain greater than 3 months' duration, 62% had daily pain, and 53% reported their pain to be moderate to severe in intensity.<sup>50</sup> The most common areas of musculoskeletal pain are the hips, knees, ankles, lumbar, and cervical spine.<sup>48</sup> Recently, Jahnsen et al found that 33% of adults with CP report chronic pain in comparison with 15% in the general population. They also found that pain was associated with low life

satisfaction, deteriorating function, and chronic fatigue.<sup>51</sup> Although pain is reduced with intervention, most adults with CP experiencing pain do not seek help from healthcare providers about their discomfort.<sup>52</sup> In addition, it may be difficult for caregivers to fully appreciate and interpret nonverbal pain behavior from persons with severe cognitive and communication impairments.<sup>52</sup> Thus, it is important to monitor individuals for behavioral changes that can be linked to pain, especially in the elderly.

Fatigue is another problem that is often reported by adults with CP and is associated with diminishing functional independence.<sup>53</sup> Adults with CP report a higher rate of physical, but not mental, fatigue than the general population and the number reporting fatigue increases with age. The greatest predictors that were associated with fatigue were low life satisfaction, bodily pain, limitations in emotional and physical role function, and deterioration of functional skills.<sup>53</sup> Fatigue was not strongly associated with type of CP; however, it was most prevalent in those reporting a moderate degree of motor impairment. These results reveal that physical fatigue is an issue in adults with CP, it increases with age, and it has an impact on preserving functional skills and life satisfaction.

Pain, fatigue, and musculoskeletal changes can ultimately lead to loss of function and independence. Very little information is available on diminishing independence in this population as they age. Recent work in Sweden<sup>54</sup> indicates that 43% of adults with CP had either decreased their walking ability or stopped walking by the age of 35. Bottos et al also found a significant decrease in walking ability in their sample of adults with CP. Most lost their ability to walk between 20 and 40 years of age.<sup>55</sup>

### Intellectual disabilities

Intellectual disability is characterized by significant limitations in both intellectual functioning and adaptive behavior (conceptual, social, and practical skills).<sup>56</sup> Accord-

ing to Krahn and colleagues,<sup>57</sup> the health status of many individuals with intellectual disabilities is adversely affected by a range of disparities, which, if addressed, can improve health outcomes. Persons with intellectual disabilities have relatively high rates of epilepsy, behavioral/mental health problems, fractures, skin conditions, respiratory disorders, and poor oral health. Older adults with severe to profound levels of intellectual disability are at risk to die from intestinal obstruction, CVDs, pneumonia, trauma, and other physical disabilities.<sup>58</sup> There were also reported cases of unrecognized problems with vision and hearing and an unnecessary increase in the use of medications for psychiatric concerns.

### PROMOTING HEALTHY AGING

Individuals with developmental disabilities living in a community need access to supportive care providers and skilled healthcare clinicians who are knowledgeable about the person, the condition of the individual, and the system of services and supports available to them. Accessing appropriate services is challenging due to an array of disparities seen in the health, rehabilitation, and social service arenas. Elders with developmental disabilities experience lower rates of preventive care and health promotion than that of the general population. Recent literature indicates concerns in the preventive screening and management of chronic conditions, obesity, nutrition, hearing, vision, functional skills, and activity level.

A greater awareness of such disparities has resulted in numerous intervention programs and practices aimed at promoting healthy aging in those with developmental disabilities. Krahn et al<sup>57</sup> describe these as *person-based*, *provider-based*, or *policy-based* practices. *Person-based practices* promote the health of persons with developmental disabilities by educating and supporting the individual in such areas as nutrition, physical activity, preventive care, rest, and the management

of stress. Programs that focus on these areas have been shown to effectively change health behaviors in adults with developmental disabilities. The *Healthy Lifestyles Curriculum*,<sup>59</sup> *The Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities*,<sup>60</sup> and *Women be Healthy: A Curriculum for Women with Mental Retardation and Other Developmental Disabilities*<sup>61</sup> are examples of structured, center-based health promotion intervention programs that promote healthy living. The *MEE Calendar*,<sup>62</sup> a less structured approach, provides a variety of activities that can be done with older adults to promote fitness and activity, maintain language skills, and facilitate problem-solving. *Provider-based practices* call for the standard and systematic inclusion of information on developmental disabilities within curricula for service providers.<sup>63,64</sup> The professional organizations of the various members of the interdisciplinary team who serve elders with developmental disabilities are including a variety of programs to increase knowledge and skill among their members, for example, training for social workers in the strengths-based care giving approach,<sup>65</sup> health promotion for nurses,<sup>66</sup> and guidelines to screen for secondary conditions for general practitioners.<sup>63</sup> *Policy-based practices* have focused on creating a system of care to improve coordination among agencies providing services to those with developmental disabilities. Service coordination, interdisciplinary care, and interagency collaboration are receiving a great deal of attention. The Special Olympics Healthy Athlete<sup>67</sup> program is one attempt to provide hearing, vision, and musculoskeletal screenings during the Special Olympics Games. In the United States, there has been a desire to increase communication between interagency and interdisciplinary groups for

addressing mental health needs in people with intellectual disabilities.<sup>68</sup> For instance, Vanderschie-Bezyak<sup>69</sup> describes a system in which 5 programs use interdisciplinary, interagency collaboration to improve mental health care for those with intellectual disabilities. These practices recognize that adults with developmental disabilities are aging and with increasing life expectancies there will be a need for a greater array of comprehensive, integrated services.

## SUMMARY

The aging of individuals with developmental disabilities has been receiving attention in literature although there is a significant paucity of information on the aging process itself and consequences of aging specific to older adults with developmental disabilities. Of paramount concern, however, is the need to integrate those with developmental disabilities into the community and allow them to live as independently as possible for as long as possible. This article provides an overview of the age-related problems seen in older adults with developmental disabilities, legal, regulatory, and policy actions taken to promote and maintain the inclusion of those with developmental disabilities in the community, and some promising intervention programs aimed at providing services for elders with developmental disabilities. Although information about this population and their rehabilitation needs is limited, it is a growing area of interest across health, rehabilitation, and social services. As the life span of individuals with developmental disabilities increases and as more elders become integrated into the community, knowledgeable service providers are needed as well as a comprehensive system of care responsive to the changing and growing needs of the population.

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